

Information Sharing and Advisory Committee (ISAC)

Recommendations, Strategies, and Performance Measures
2019 Updates





Recommendation 1: Assure Effective Communication

Every person has an effective way to communicate in order to express choice and ensure his or her health and safety. All forms of communication should consider and include the individual's language preferences and use of current technology.

Strategies:

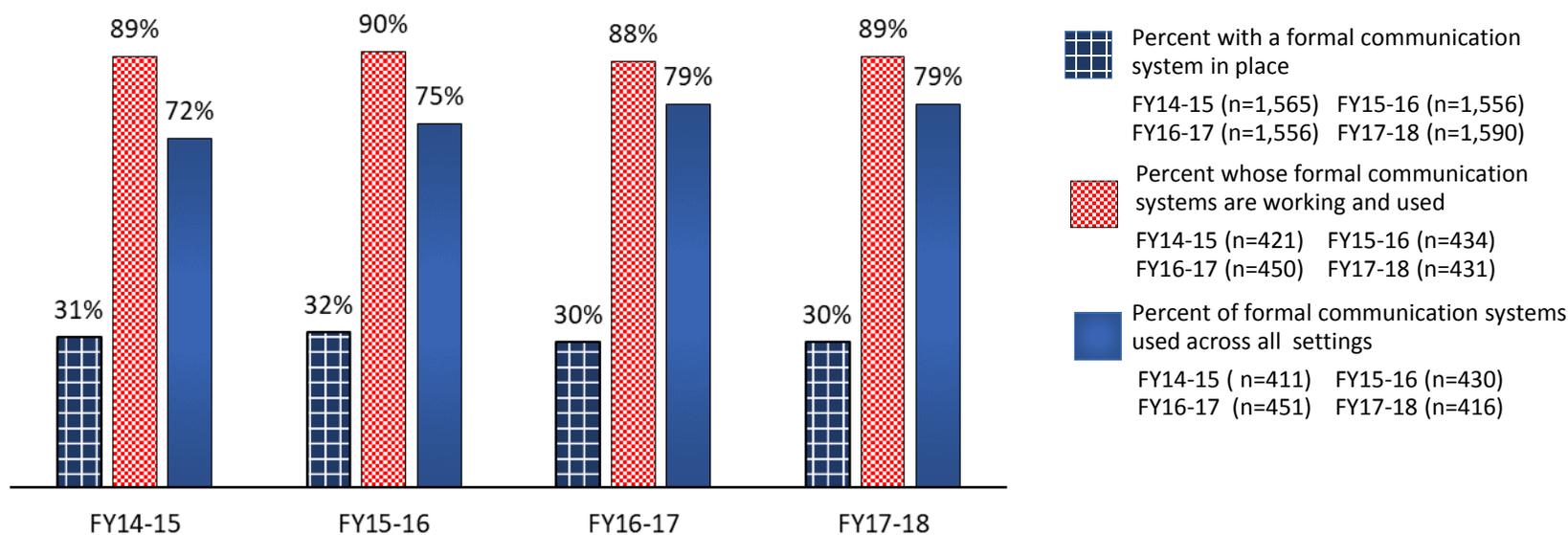
1. Finalize and issue the communication policy bulletin. **(Retained/Resumed)**
 - Define communication:
 - It is a right;
 - It is expressive and receptive;
 - It is a meaningful interaction not just words/signs;
 - It is cultural;
 - It is foundational to leading a self-determined life, being a part of a community, being healthy and safe, and having healthy relationships;
 - It will assert that everyone can communicate in one way or another (such as but not limited to behavior, eye gaze, visual gestural); however, not everyone can communicate effectively and meaningfully.
 - Describe a communication profile and plan;
 - Specify roles and expectations;
 - Include the applicable 6100 regulations.
2. Incorporate a focus on communication in the individual planning process. **(Retained)**
3. Identify all possible funding avenues (including private insurance, ACCESS (Medicaid), Medicare, Person/Family Directed Services (P/FDS), waivers, etc.) to support people in exploring effective communication supports. These would include formal assessments to identify needs and appropriate approaches, techniques, devices, updates, and training. **(Retained)**
4. Address the lack of Communication Specialists and clinicians, such as speech-language professionals and board-certified behavior analysts, with the expertise in communication to work with individuals with intellectual disabilities or autism. **(Updated)**
5. Recognize and accommodate the primary language of individuals, self-advocates, and families; provide materials and translation. **(Retained)**
6. Promote generic social change by building capacity in understanding and supporting people with nontraditional communication needs. **(New)**
7. Track progress by measuring compliance with revised regulations relating to communication. **(New)**

Performance Measures:

1. For people who do not communicate effectively using words, the percent of people with a communication system in place, i.e., a written plan in place that describes and documents a communication system (e.g., sign language, a picture board/system such as Picture Exchange Communication System (PECS), a voice-output communication device, or a combination of methods). A communication profile in the ISP is not sufficient in and of itself. **(Source: Independent Monitoring for Quality (IM4Q)) (Updated)**
2. For people with communication systems in place, the percent of systems that are in working order and being used. **(Source: IM4Q) (Updated)**
3. For people with communication systems in place, the percent of individuals and self-advocates who report using them across all settings (i.e., you use the system at home, at work, at school, and in your community). **(Source: IM4Q) (Updated)**
4. Percent of individuals who report that their staff understand their communication. **(Source: IM4Q) (New)**

5. Percent of individuals that have a communication need identified and have the need addressed in the ISP. **(Source: QA&I) (New)**
6. Percent of individuals for whom the Supports Coordinator (SC) explores with the individual options for communication assistance when appropriate and supports the individual to choose. **(Source: QA&I) (Retained)**
7. Number of individuals who received the Enhanced Communication Rate for services (with 'U1' procedure modifier). **(Source: Provider Reimbursement & Operations Management Information System in Electronic format (PROMISE™)) (Retained)**

1,2&3. For individuals and self-advocates who do not communicate using words



Source: IM4Q Survey

4. Percent of individuals who report that their staff understand their communication

63%
n=2,559



Source: IM4Q 2017-2018 Survey

6. Percent of individuals whose supports coordinators explore with the individual options for communication assistance when appropriate and support the individual to choose

67%
n=67



FY17-18

95%
n=58



FY18-19

Source: QA&I FY2018-2019



Recommendation 2: Promote Self-Direction, Choice, and Control

Personal choice and control over all aspects of life must be supported for every person. Choice about where to live, whom to live with, what to do for a living, and how to have fun all are key choices in life, as are seemingly small choices: such as what to eat, what to wear, when to wake up in the morning, and when to go to bed. It is important to be able to trust the people who provide assistance, to feel confident that they respect you and your right to manage your life, and to enjoy each other's company.

Self-direction works when individuals have clear and understandable information, opportunities to exercise choice, and assistance with making decisions when needed. Self-direction is only possible when family, friends, and people who provide supports respect the individual's preferences and their right to make mistakes, and facilitate the implementation of the individual's decisions.

Strategies:

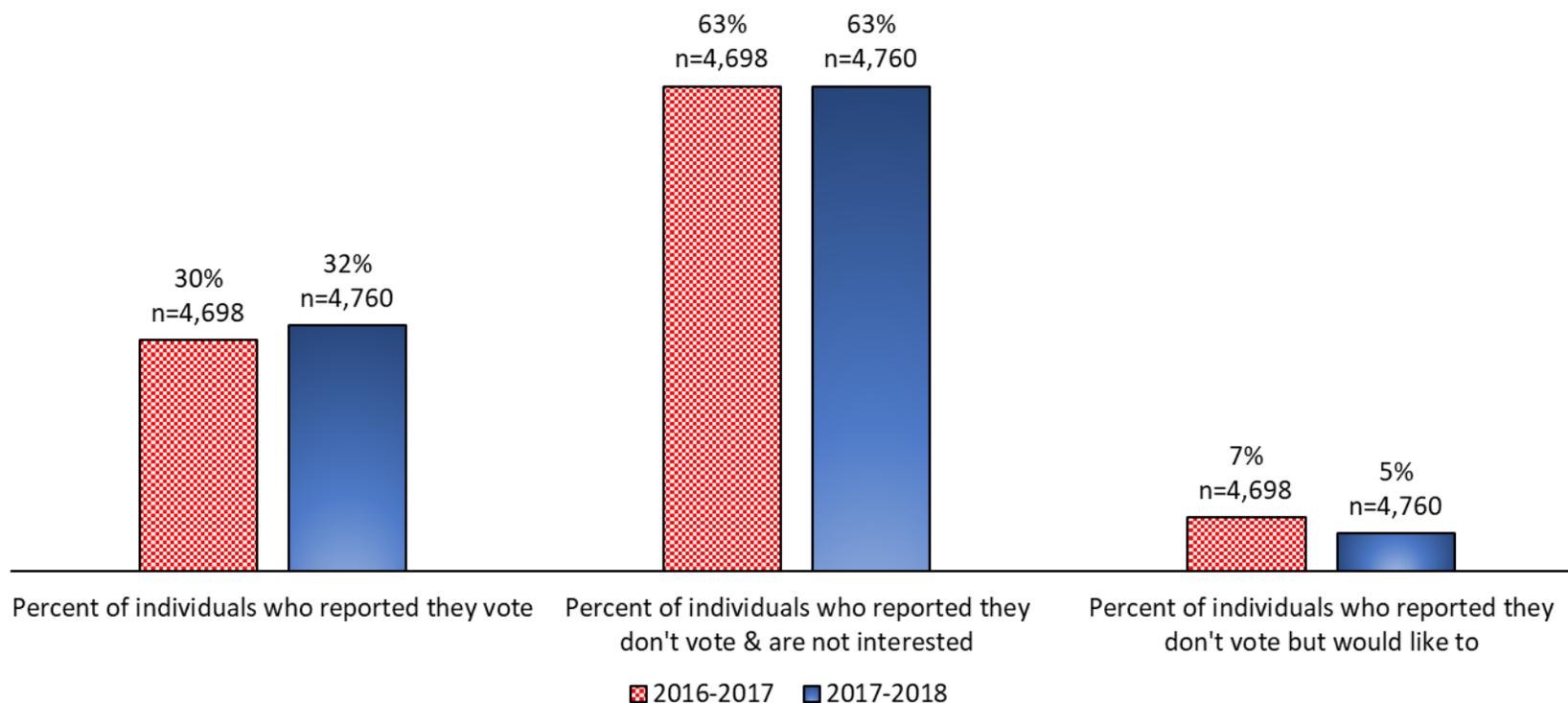
1. Simplify the process for people to direct their services to reduce time and effort needed to use the model. **(Retained)**
 - Revise/simplify the PA Guide to Participant-Directed Services (PDS) to make the guide more accessible to people unfamiliar with PDS models;
 - Simplify bulletins and announcements about Vendor/Fiscal Employer Agent (VF/EA) and Agency with Choice (AWC) to establish clear and consistent expectations for VF/EA and AWC performance;
 - Clarify the documentation required to comply with state and federal regulations regarding PDS services.
2. Provide information and education about self-direction to individuals, self-advocates, families, supports coordinators, and providers. **(Retained)**
 - Provide training to participants, common-law employers, supports service workers, and natural supports on real world methods to manage the self-direction process in the VF/EA and AWC models through the PA Family Network and Self Advocates United as 1;
 - Conduct targeted outreach to AEs/SCOs with low participation in PDS to encourage increased use of PDS;
 - Support the PA Family Network to educate families about the self-direction option.
3. Assure the availability of fiscal intermediary services. Permit more than one AWC to operate within a county/AE, allowing greater access to AWC services and expanded participant choice. **(Retained)**
4. Provide training to Agencies with Choice. Provide training to AWCs on operation and ODP recommendations to increase consistency of practice. **(Retained)**
5. Ensure personal choice and control over all aspects of life are supported for every person. **(New)**
 - Apply the "Individual Rights" sections of Chapter 6100 to support choice and control over all aspects of individuals' everyday lives;
 - Use data analytics to track and measure results, and to help support the provision of technical assistance and training.
6. Build capacity in understanding and supporting people with nontraditional communication needs with an emphasis on self-direction, choice, and control. **(New)**
 - Communicate expectations regarding the link between effective communication and the ability to control one's own life.

Performance Measures:

1. Number of Individuals and Self-Advocates who use PDS, by AWC and VF/EA. **(Source: HCSIS) (Retained)**
2. Number of Self-Directed Services per individual/self-advocate; will include support broker service. **(Source: HCSIS) (Retained)**
3. Percent of individuals and Self-Advocates who use PDS, including AWC and VF/EA. **(Source: HCSIS) (Retained)**
4. Percent of individuals who reported they vote. **(Source: IM4Q) (New)**

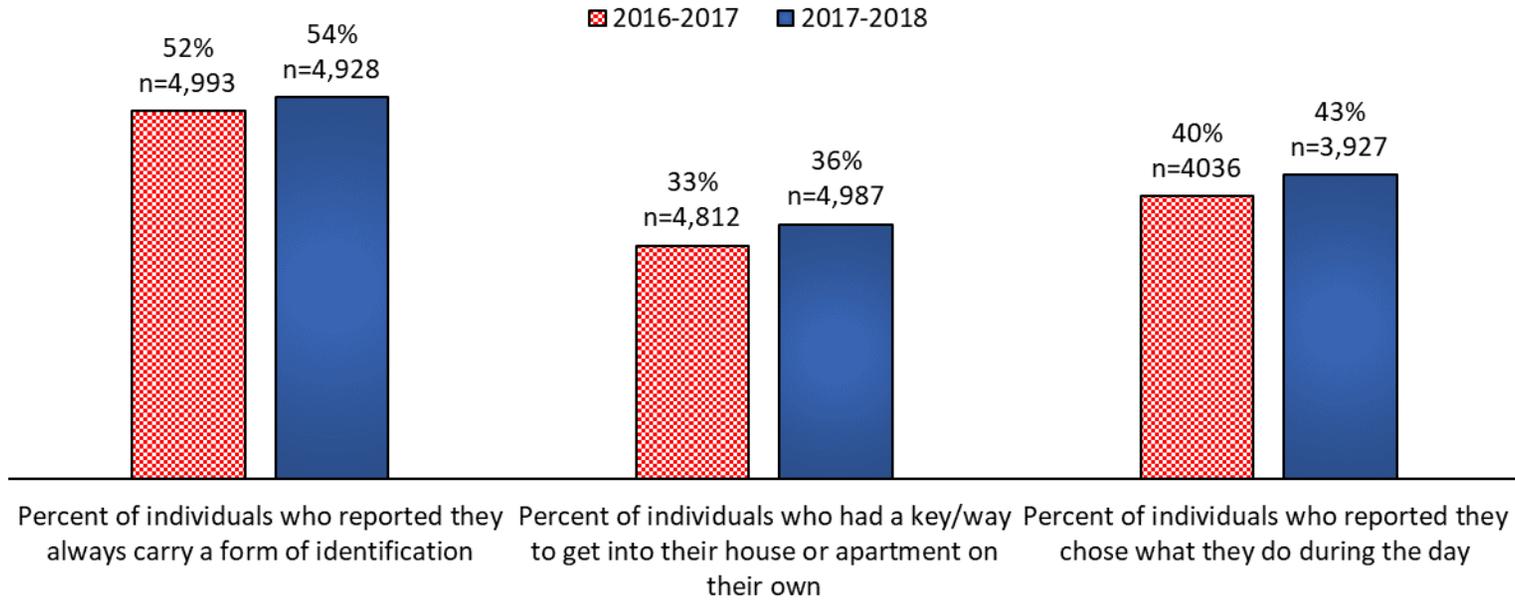
5. Percent of individuals who report they always carry a form of identification. *(Source: IM4Q) (New)*
6. Percent of individuals surveyed who had a key/way to get into their house or apartment on their own. *(Source: IM4Q) (New)*
7. Percent of individuals interviewed who reported they chose what they do during the day. *(Source: IM4Q) (New)*
8. Percent of individuals who said they were given a choice to live where people without disabilities live. *(Source: IM4Q) (New)*
9. Percent of individuals surveyed who saw no other places before they moved into their residence. *(Source: IM4Q) (New)*

4. Percent of individuals who said they vote

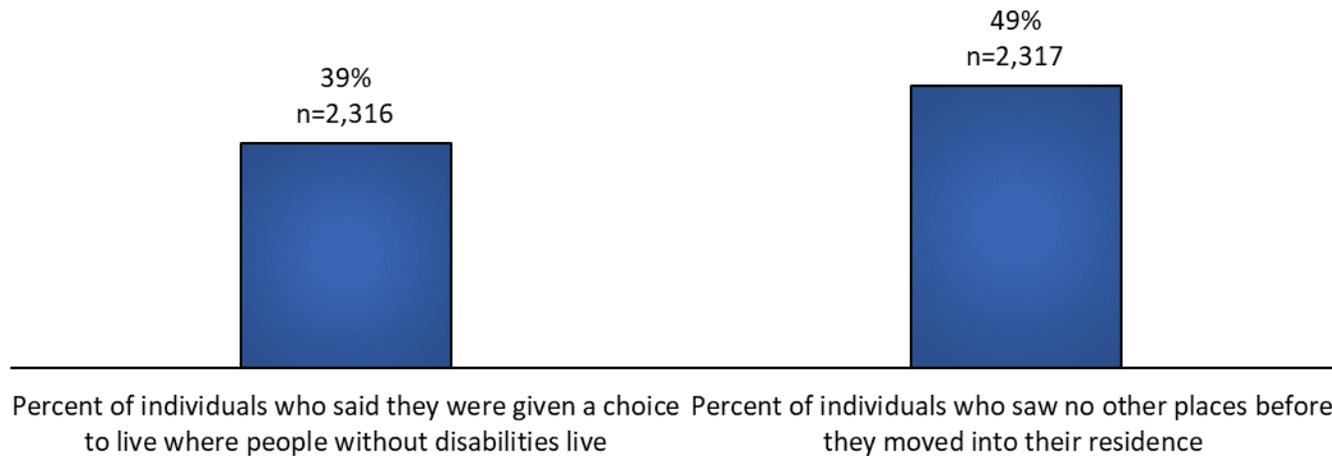


Source: IM4Q Survey

5, 6 & 7. Choice and Control at home and during the day



8 & 9. Choice and Control on where to live



Source: IM4Q 2017-2018 Survey



Recommendation 4: Support Families throughout the Lifespan

The vast majority of people with disabilities in Pennsylvania live with their families. Families need support in order to make an everyday life possible throughout the person's lifetime. Families need information, resources, and training. They need connections with other families and support services. Listening to people with disabilities and their families is key to providing supports that help them achieve an everyday life.

Strategies:

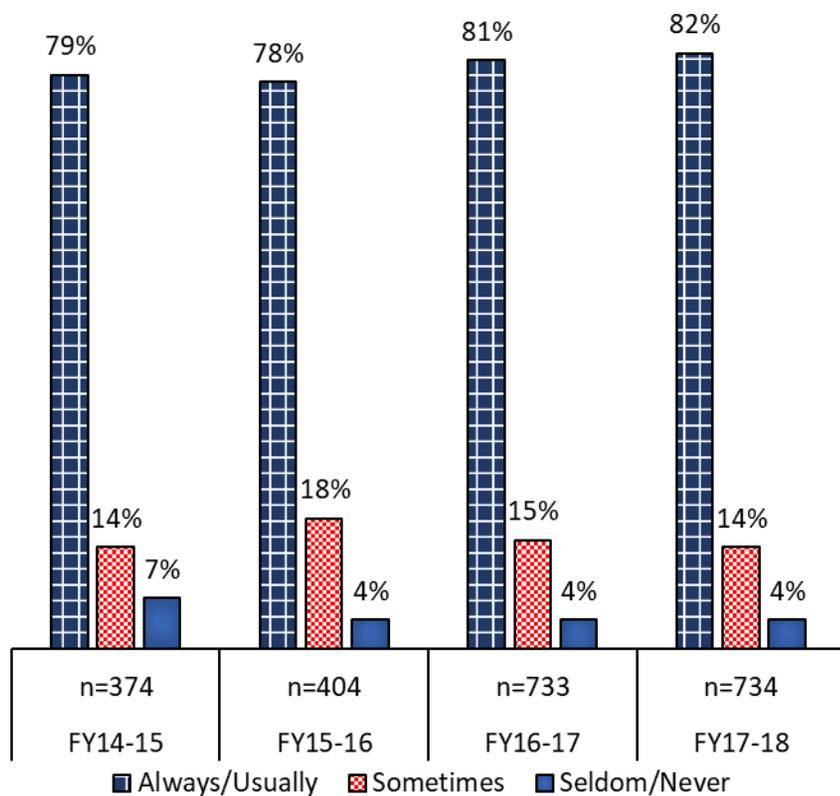
1. Recognize that family is defined by the person; by who is important to the person. It may include biological and chosen family or staff. **(Retained)**
2. Support the work of the PA Family Network to reach families with a consistent message of the importance of family expectations of a good life for family members and opportunities for discovery and navigation of support/service systems and community-based resources. **(Retained)**
3. Support the continued growth of regional collaboratives, through the Community of Practice, so that communities and all stakeholders experience genuine direction and ownership in local approaches to ensure equal access and support of individuals and families. **(Revised)**
4. Align supports coordination with the LifeCourse Framework so that SCs have the skills and capacity to encourage, explore, and plan with self-advocates and families about their vision of a good life. **(Retained)**
5. Amend the ISP to address families' needs, including challenges a family faces, the vision for the individual, and extended family information. **(Retained)**
6. Develop materials that lead families to: information, connections, opportunities, supports, and resources needed to build everyday lives for all. **(Retained)**
7. Strategize multiple ways to disseminate information to families. Communication avenues include: counties, providers, email distribution lists, school districts, advocacy organizations, social media, and traditional media at the local and state level. **(Retained)**
8. Focus on the engagement of cross-systems partners in the Community of Practice to recognize their roles in supporting families to have strong visions and high expectations. The value their roles play in improving access for families to needed information, supports, and services throughout the lifespan is essential. **(Revised)**
9. For people who are waiting for supports and services, utilize the supports coordination service, Targeted Support Management, to support community navigation through the LifeCourse Framework and tools for planning, connecting with other families, and finding information and resources within their communities. **(Revised)**

Performance Measures:

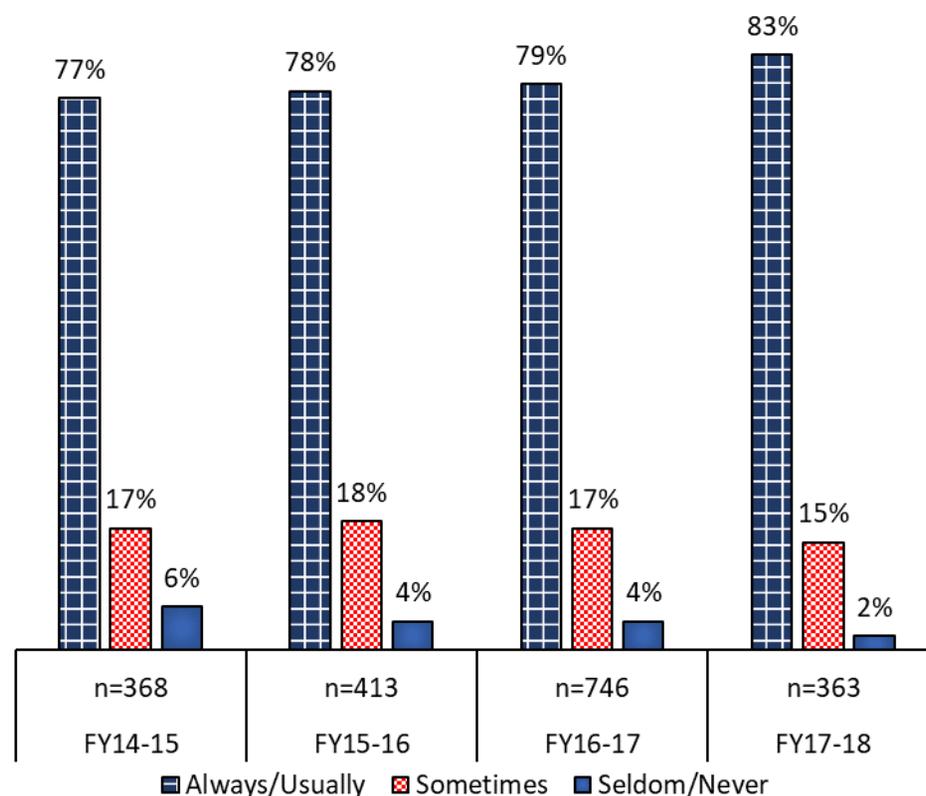
1. Percent of family members who receive enough information that helps them participate in planning services for their family. **(Source: NCI PA Adult Family) (Retained)**
2. Percent of family members who report that the information received is easy to understand. **(Source: NCI PA Adult Family) (Retained)**
3. Percent of family members reporting the Supports Coordinator tells them about other public services for which their family is eligible (food stamps, supplemental security income (SSI), housing subsidies, etc.) **(Source: NCI PA Adult Family) (Retained)**
4. Percent of relatives who reported they have an opportunity to connect and network with other families with relatives at similar life stages. **(Source: IM4Q) (New)**
5. Percent of relatives who said they were aware of the PA Family Network. **(Source: IM4Q) (New)**
6. Of those relatives who said they were aware of the PA Family Network, the percent who reported they had attended a workshop led by the Network of Family Advisors. **(Source: IM4Q) (New)**
7. Percent of respondents whose family member transitioned from school to adult services in the past year who were happy with the process. **(Source: IM4Q) (New)**

- 8. Percent of respondents who reported they had learned about the LifeCourse framework and tools. *(Source: IM4Q) (New)*
- 9. Percent of relatives who reported the services coordinator asks about their vision for an everyday life for their family member. *(Source: IM4Q) (New)*

1. Percent of Family Members Who Receive Information to Help Plan Services

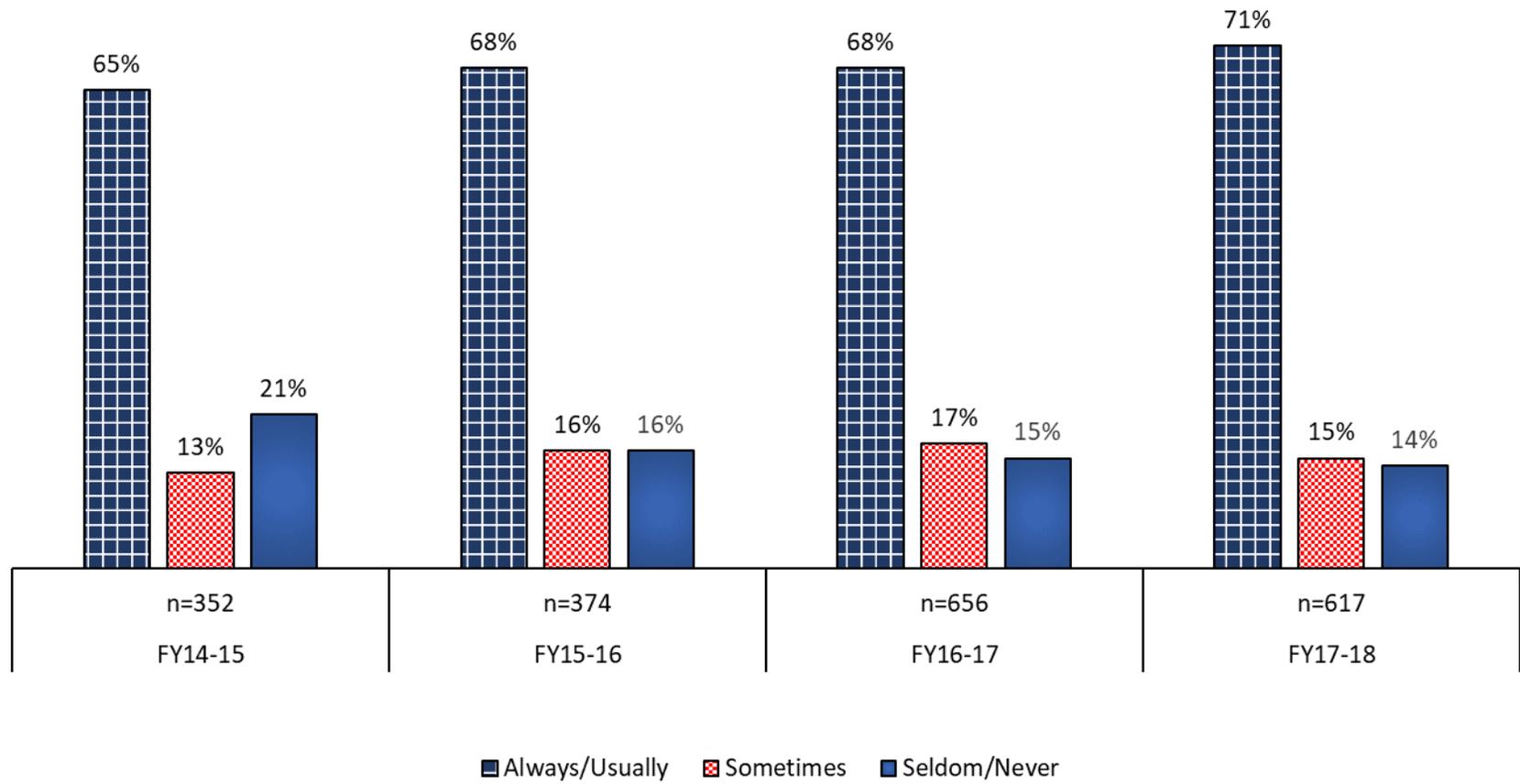


2. Percent of Family Members Who Report Information About Services is Easy to Understand



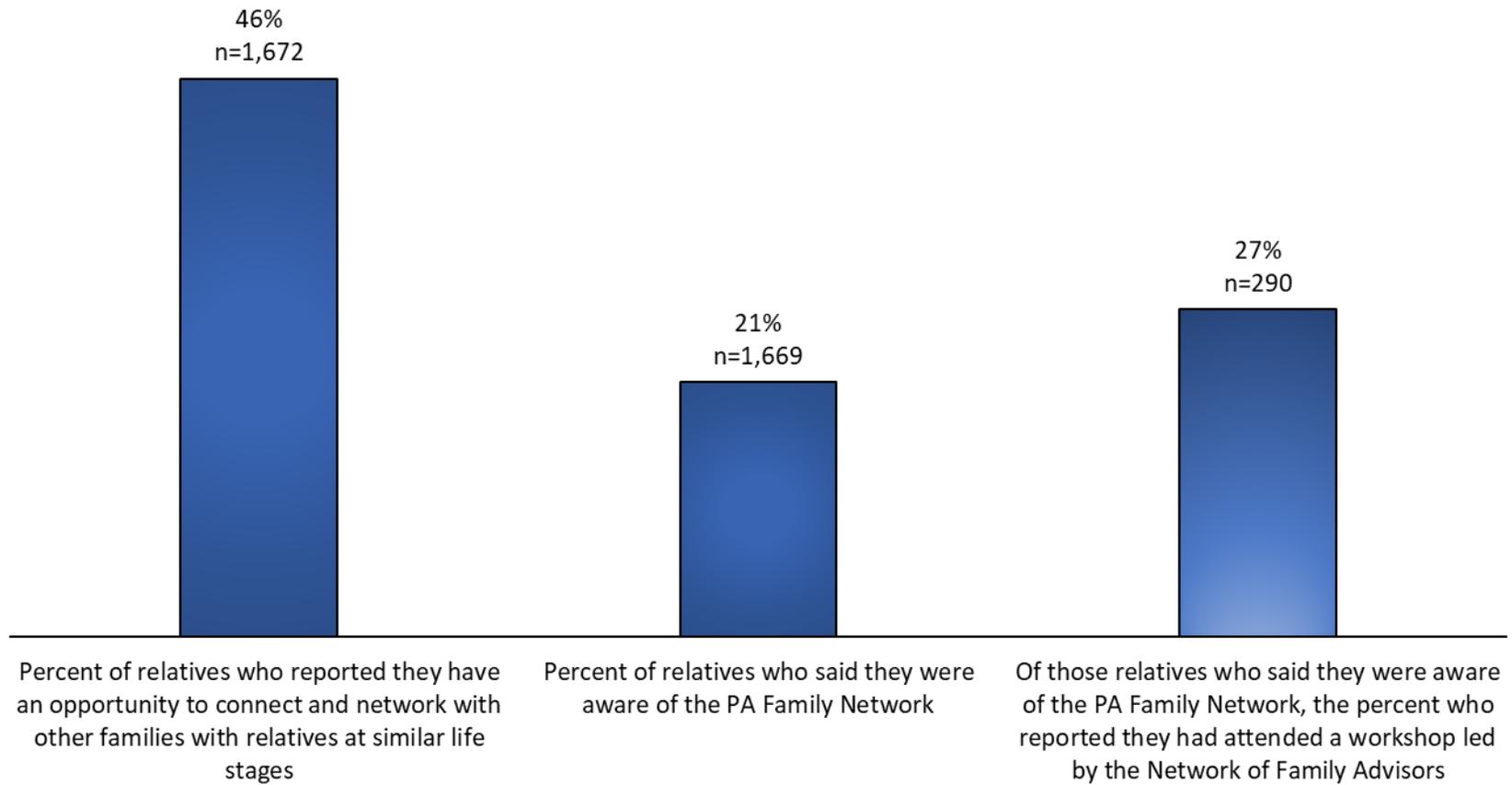
Source: NCI PA Adult Family Survey

3. Percent of Family Members Who Report SCs Tell Them About Other Public Services



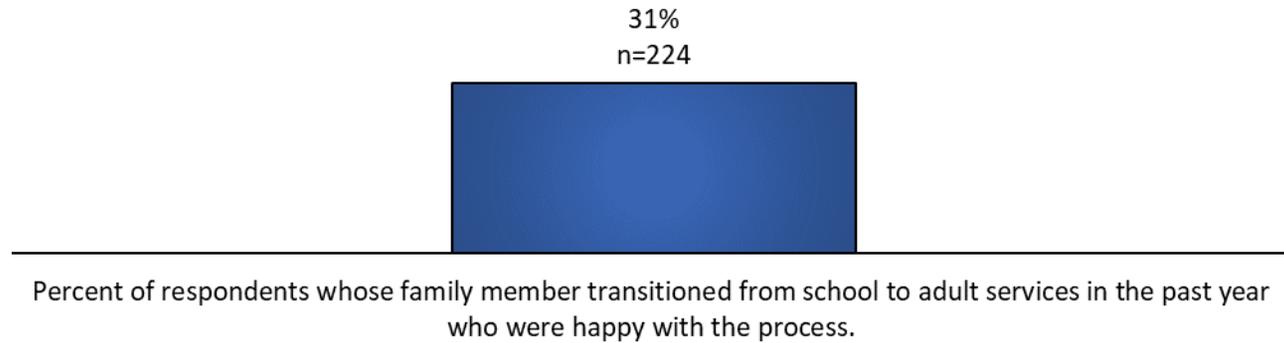
Source: NCI PA Adult Family Survey

4, 5 & 6. Individuals and Families Networking



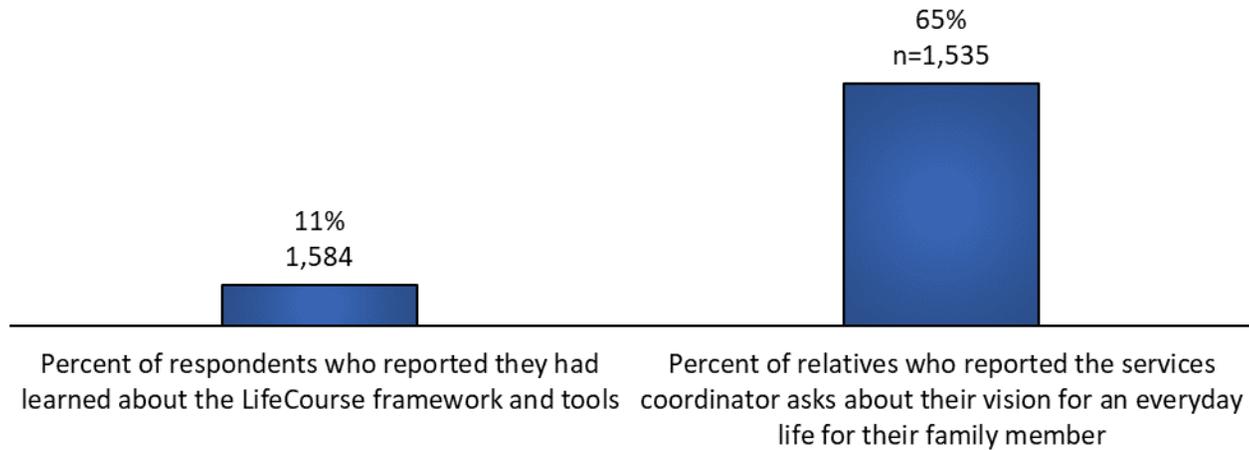
Source: NCI PA Adult Family Survey

7. Transitioning From School to Adult Services



Source: IM4Q 2017-2018 Survey

8 & 9 . Individuals' Vision and the LifeCourse Framework



Source: IM4Q 2017-2018 Survey



Recommendation 5: Promote Health, Wellness, and Safety

Promote physical and mental health, wellness, and personal safety for every individual and his or her family. Promoting physical and mental health means providing information about health and wellness, emotional support, and encouragement. Tools that help every individual adopt a healthy lifestyle — including good nutrition, healthy diets, physical activity, and strategies to reduce and manage stress and protect oneself from all types of abuse and exploitation — must be provided.

Strategies:

Overarching plan to meet above recommendation: Develop and implement a comprehensive program of wellness opportunities for people with IDD and autism. Areas including: diet/nutrition; physical activities; emotional wellness; sexuality and healthy relationships; wellness as related to aging; safety and drugs and alcohol. To support the utilization of health, wellness and safety opportunities, increased health literacy will be promoted. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. **(Revised)**

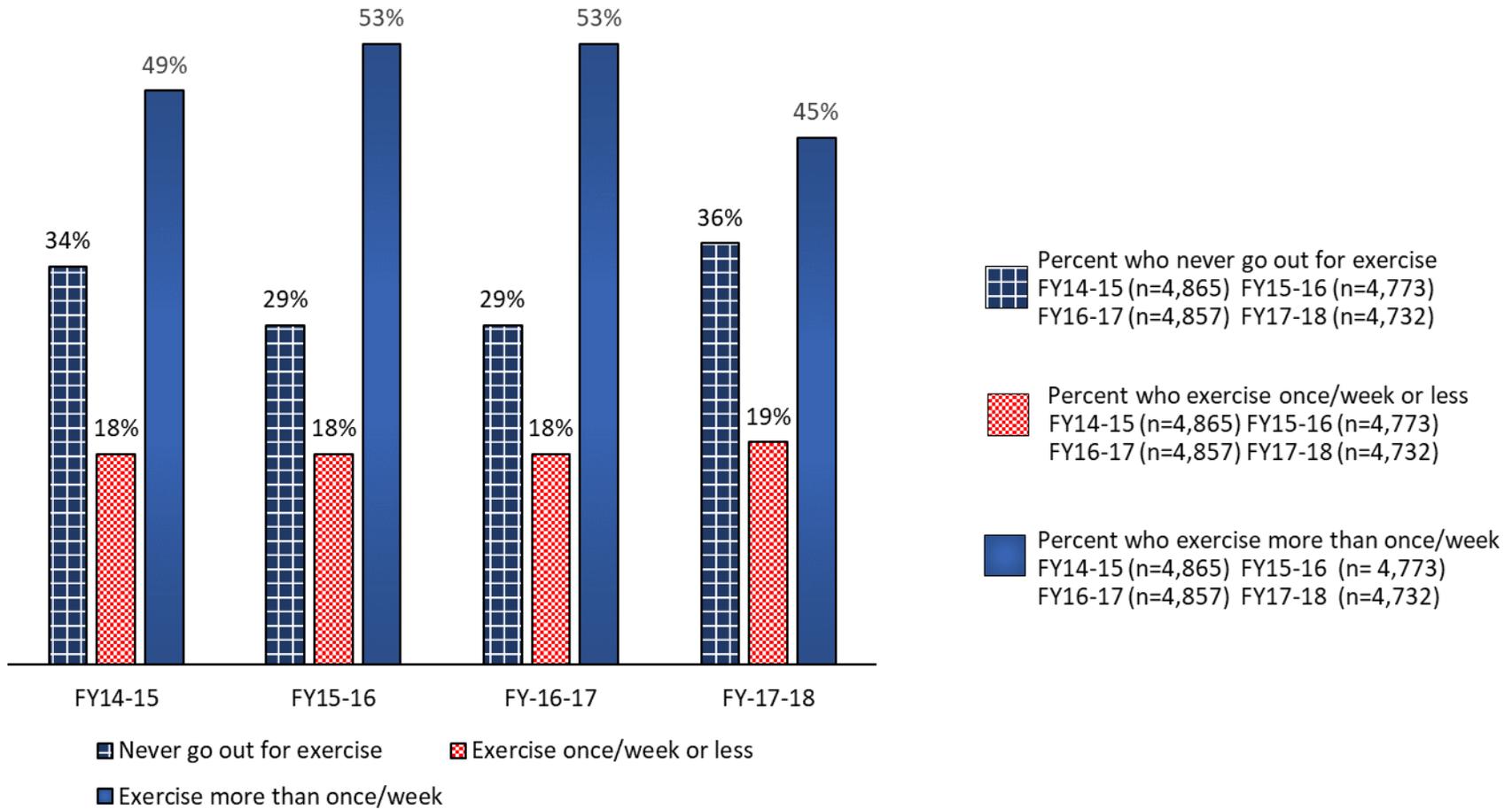
1. Direct people to existing resources with information on healthy living. **(Retained/Updated)**
 - Create a resource guide with available resources by region, and post online;
 - Provide outreach and education for Supports Coordinators on these topics to promote incorporation into the ISP;
 - Continue to promote waiver services among professionals to become eligible providers for available waiver services for wellness;
 - Promote health literacy to increase individuals' capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.
2. Increase the use of Mental Health First Aid (MHFA) among stakeholders across the state. **(Retained)**
3. Update, disseminate, and provide training on sexuality guidelines. **(Retained/Updated)**
 - Identify experts in the field in PA available to support individuals and families with recommendations and strategies.
4. Incorporate a focus on health and wellness into the individual planning process. **(Retained)**
 - Use the Health Risk Screening Tool (HRST) to inform individual planning;
 - Offer training on the Fatal Four to broader audiences in both live and on-line formats.
5. Health Care Quality Units will develop outreach to promote wellness to individuals and self-advocates living with families, including people on the waiting list, engaging partners including ASERT, SAPNA, the PA Family Network, and Temple. **(Retained/Updated)**
6. Broaden the use of physical and behavioral health data to understand health, wellness and safety needs and risks, and to inform ODP planning and direction of supports such as waiver development, HCQU and ASERT activities. **(New)**

Performance Measures:

1. Regarding monthly exercise, percent of individuals who report they:
 - Never go out for exercise;
 - Exercise less than weekly;
 - Exercise once a week;
 - Exercise more than once a week. **(Source: IM4Q) (Retained)**

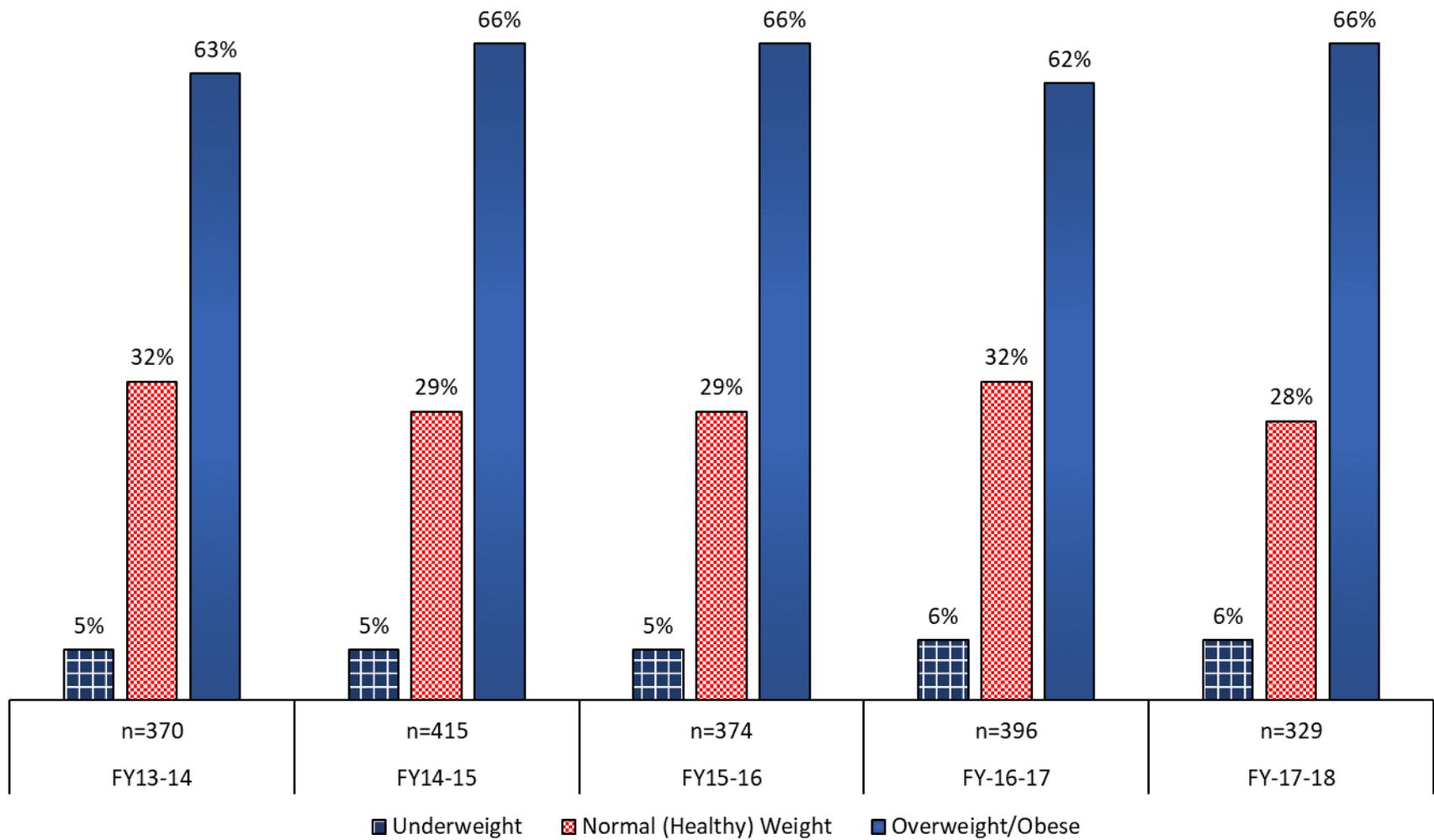
2. Percent of individuals who are underweight, normal weight, overweight, and obese. *(Source: NCI PA Adult Consumer Survey) (Retained)*
3. Percent of individuals with medical, dental, and eye exams in the past year. *(Source: NCI PA Adult Consumer Survey) (Retained)*
4. Percent of individuals and self-advocates who routinely engage in physical activity at least once a week for at least 10 minutes. *(Source: NCI PA Adult Consumer Survey) (Updated)*
5. Percent of individuals who report that communication in their doctor's office is effective, including:
 - Percent who report if they needed help communicating at the doctor's office, it was available;
 - Percent who reported they have the opportunity to discuss health with their primary care provider;
 - Percent who reported their doctor speaks directly to them during appointments;
 - Percent who feel they understood their doctors' instructions;
 - Percent who reported they feel their doctor understands them. *(Source: IM4Q) (New)*
6. Percent of individuals who report they can access necessary medical services, including:
 - When asked how hard it is to get health care services in their community, percent who reported it was very easy or pretty easy, in-between, or very hard or hard;
 - When asked how hard it is to get dental services in their community, percent who reported it was very easy or easy, in-between, or very hard or hard;
 - Percent who reported they have not been prevented from receiving medical and dental services because of their disabilities;
 - Percent who reported they were able to see a medical specialist if they needed to;
 - Percent who said they were not able to see a specialist due to barriers.
 - Percent who reported they have the opportunity to discuss health concerns with the psychiatrist;
 - Percent who reported they do not have the opportunity to discuss health concerns with the psychiatrist.
 - Percent of individuals who reported they do not have a psychiatrist but want one. *(Source: IM4Q) (New)*
7. Percent of individuals who reported they are able to provide consent for medical treatment. *(Source: IM4Q) (New)*
8. Of those able to provide consent for medical treatment, percent who said their doctor accepts their consent. *(Source: IM4Q) (New)*

1. Percent of Individuals and Self-Advocates Who Exercise



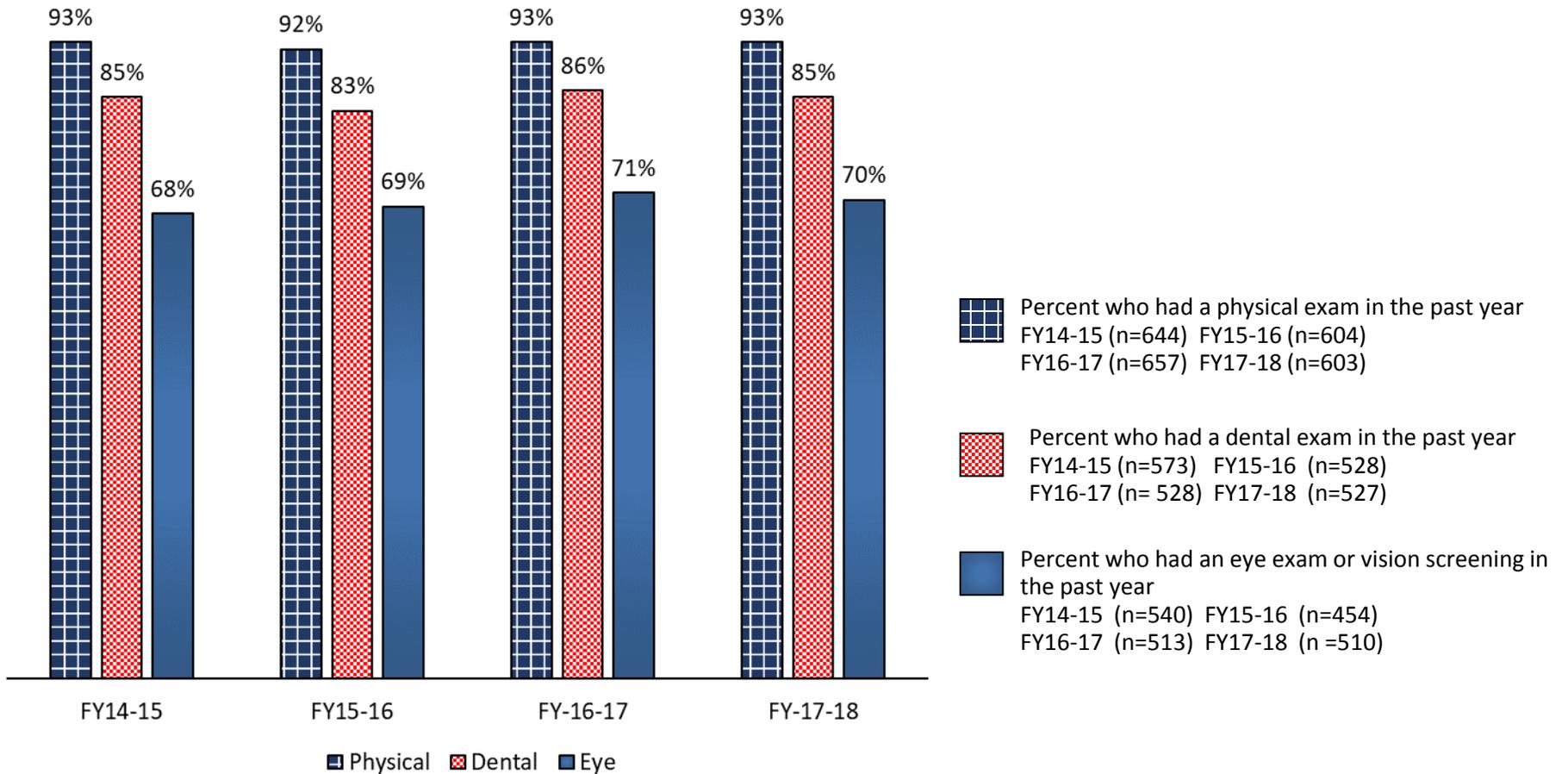
Source: IM4Q 2017-2018 Survey

2. Percent of Individuals and Self-Advocates who are Underweight, Normal Weight, Overweight, or Obese



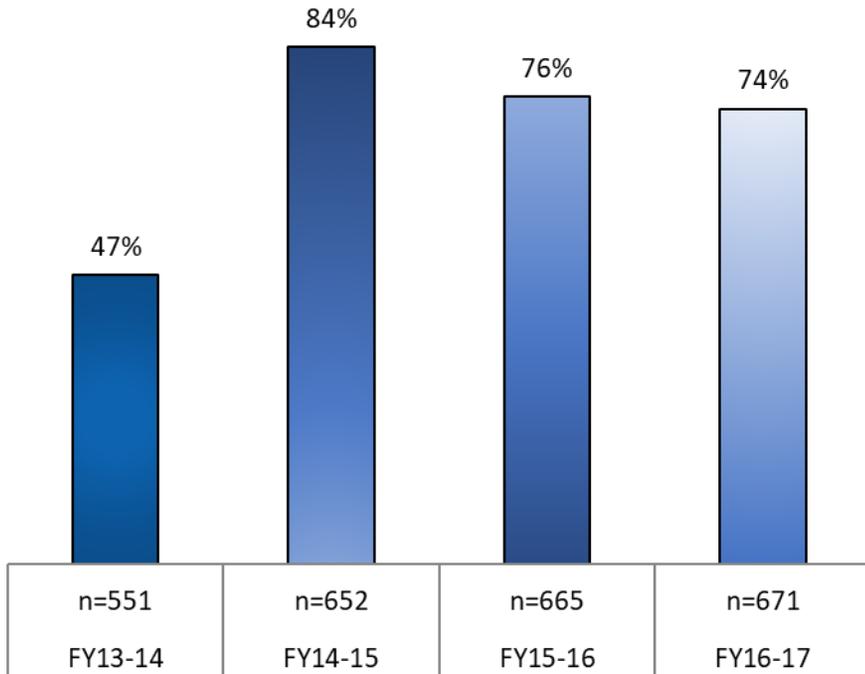
Source: NCI PA Adult Family Survey

3. Percent of Individuals and Self-Advocates Who Have Had Physical, Dental, and Eye Exams in the Past Year

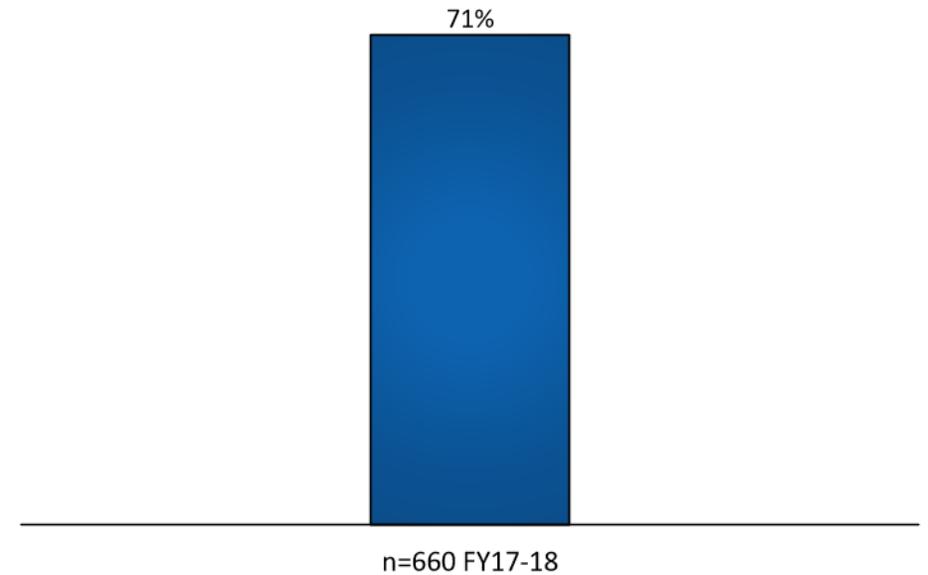


Source: NCI PA Adult Family Survey

4. Percent of Individuals and Self-Advocates who Routinely Engage in Moderate Physical Activity (FY13-14, 14-15); in Regular Physical Activity (FY15-16)



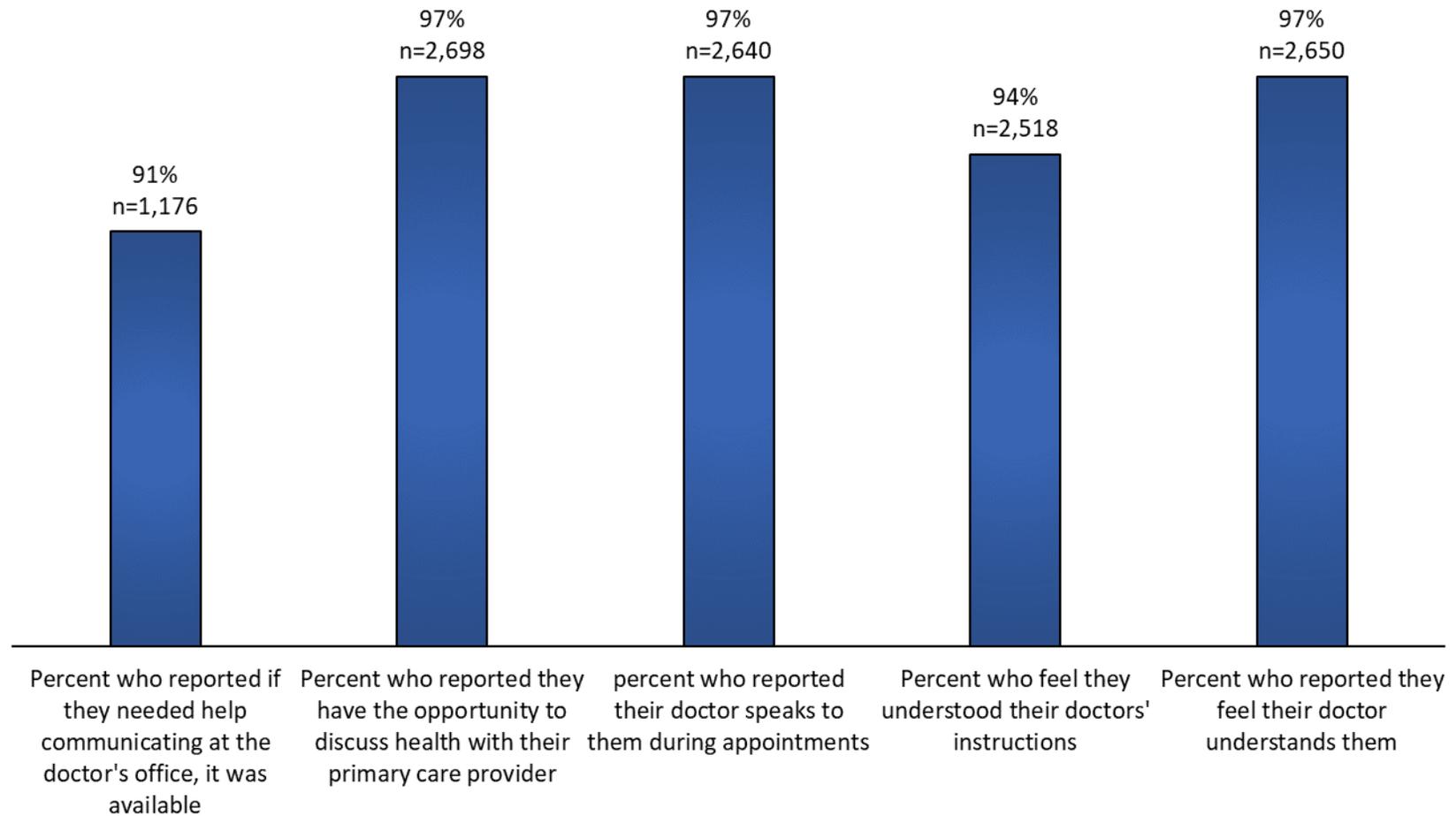
4. Percent of individuals who exercise or do physical activity at least once a week at least 10 minutes at a time



Notes – Moderate physical activity is an activity that causes some increase in breathing or heart rate. Examples include: brisk walking, swimming, bicycling, cleaning, and gardening. In 2016, the term Moderate Physical Activity was changed to Regular Physical Activity.

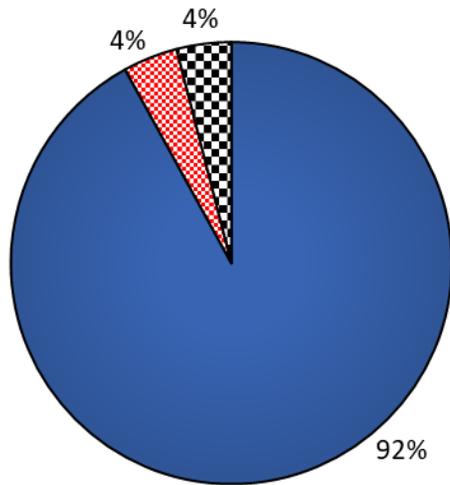
Source: NCI PA Adult Family Survey

5. Percent of individuals who report communication in their doctor's office is effective

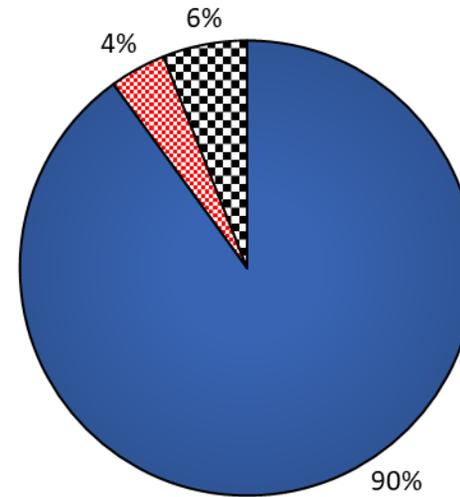


Source: IM4Q 2017-2018 Survey

6. Percent of individuals who reported they can access necessary medical services



Percent who reported it was easy, in-between, or hard to get health care services in their community (n=2,395)

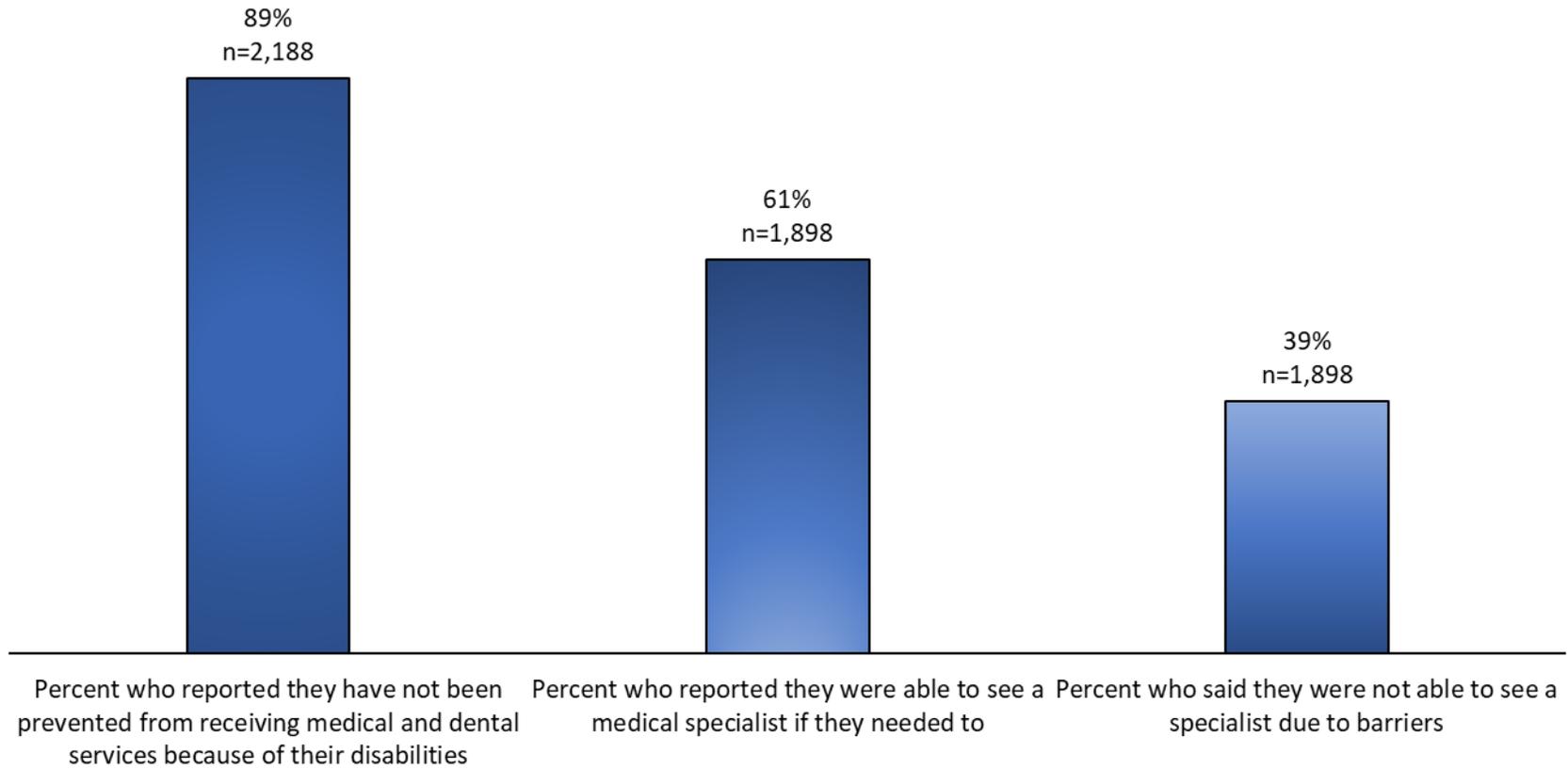


Percent who reported it was easy, in-between, or hard to get dental services in their community (n=2,420)

■ very easy or easy ■ in-between ■ very hard or hard

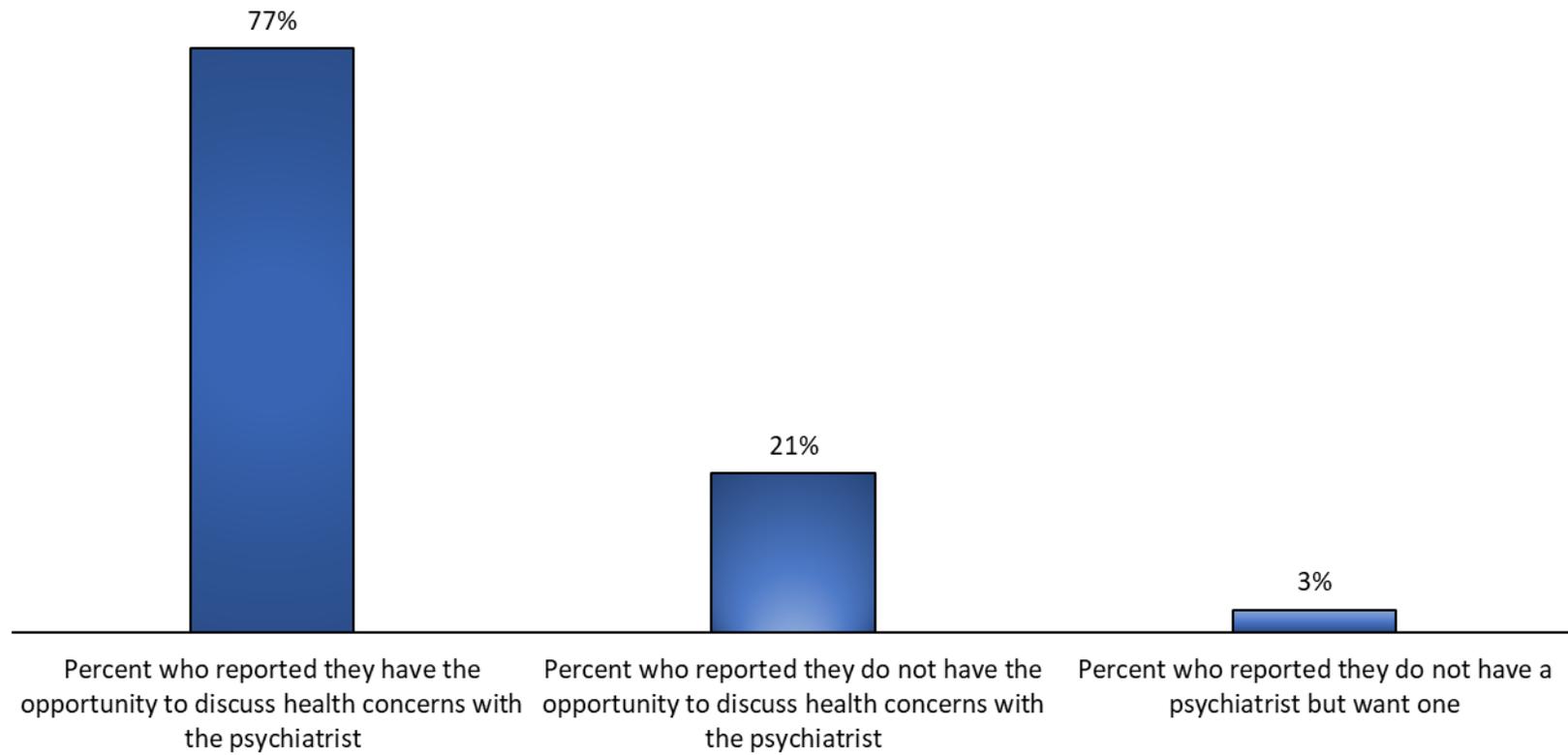
Source: IM4Q 2017-2018 Survey

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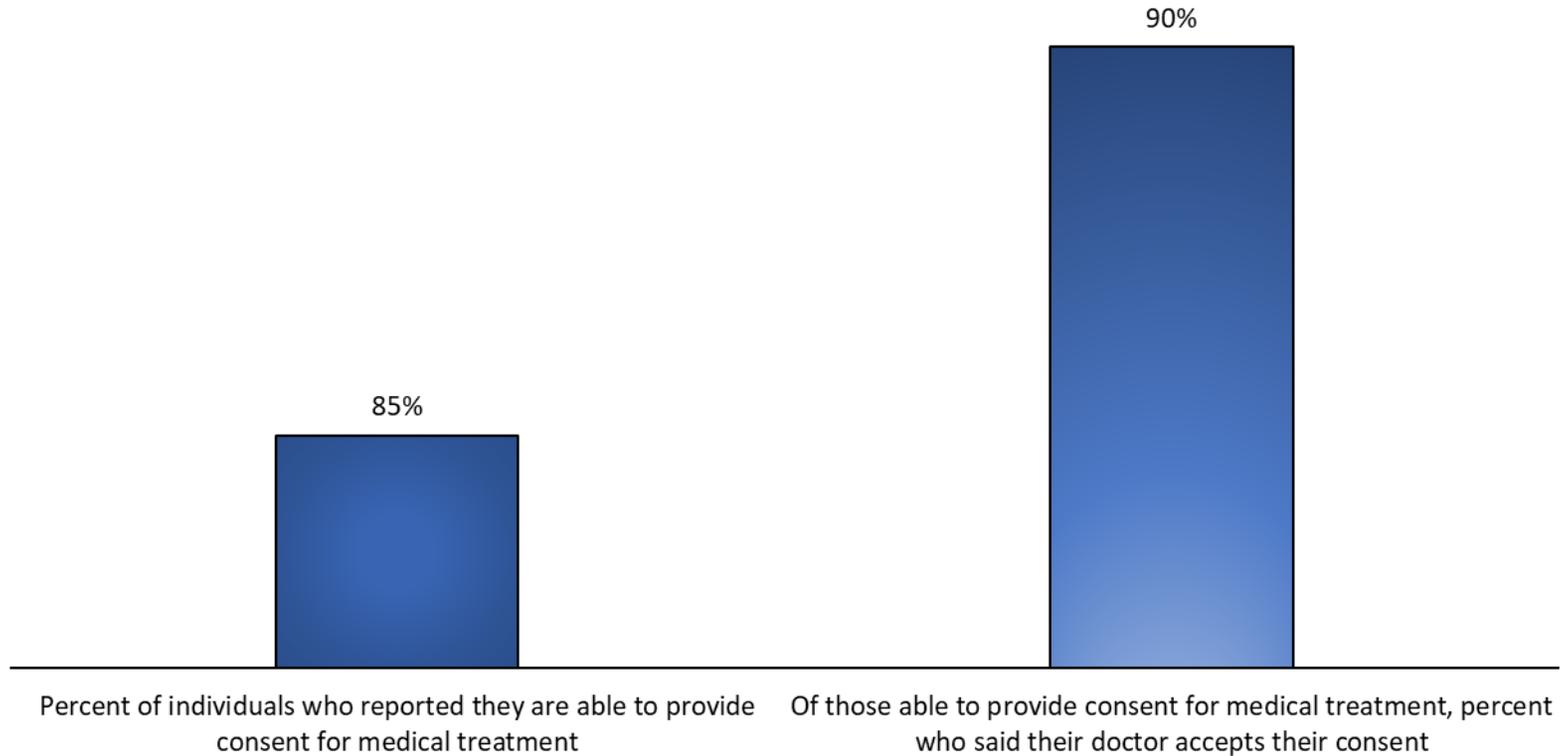
Source: IM4Q 2017-2018 Survey

6. Percent of individuals who reported they can access necessary medical services
(n=1,511)



Source: IM4Q 2017-2018 Survey

7 & 8. Consent at the Doctors' Office (n=1,734)



Source: IM4Q 2017-2018 Survey



Recommendation 9: Improve Quality

Together we must plan and deliver services and supports that adhere to our values, measure person-centered outcomes, and continuously improve an individual's quality of life. All stakeholders must be engaged in the process of measuring how well services assist people in achieving an everyday life.

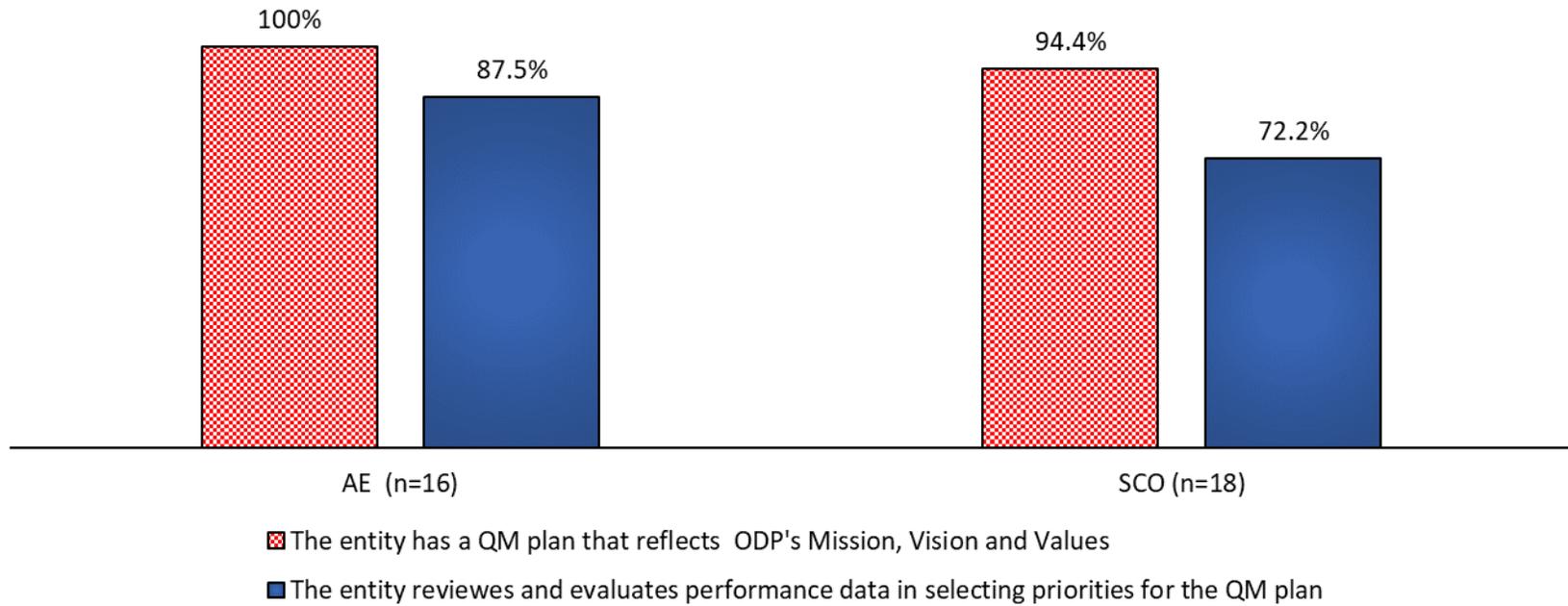
Strategies:

1. Maintain the Information Sharing and Advisory Committee (ISAC) as ODP's Stakeholder Quality Council, the entity that creates a detailed series of recommendations, strategies, and performance measures to guide the Office of Developmental Programs (ODP) and gauge its progress in achieving the important goals put forth in Everyday Lives. The ISAC will continue to use the quality improvement framework to plan and implement improvements, assess whether we achieve outcomes as intended, make changes as needed, and embed successful practices in the system. **(New)**
2. Continue to offer ODP's QM Certification Curriculum to build system capacity in applying quality management principles and practices across the system. **(New)**
3. Develop and disseminate an ODP annual report to show the implementation of approved recommendations and strategies across the system. **(Retained)**
4. Create a provider profile to assist individuals, self-advocates, families, and supporters to make informed choices about providers and services. **(Updated)**
5. Develop, implement, and maintain Quality Assessment and Improvement (QA&I) process as ODP's annual monitoring of the system's performance in supporting individuals and families. **(New)**

Performance Measures:

6. Number of ODP and stakeholder staff who achieve ODP QM Certified status. **(Source: MyODP.org) (Retained)**
1. ODP develops and distributes annual reports, including the ISAC Annual Report, ODP's Annual Data Report, the Annual QA&I Aggregate Report of Self-Assessment and the Annual QA&I Statewide Report. **(Updated)**
2. ODP, in collaboration with the ISAC, uses all available data and identifies the need for new data collection to measure and improve performance.
3. Number and percent of AEs, SCOs and Providers whose QM Plans reflect ODP's Mission, Vision and Values. **(Source: QA&I) (Retained)**
4. Number and percent of AEs, SCOs and Providers that review and evaluate performance data in selecting priorities for QM Plans. **(Source: QA&I) (Retained)**
5. Number and percent of AEs, SCOs and Providers that use self-assessment results to work on quality improvement annually. **(Source: QA&I) (Retained)**

4 & 5. Administrative Entities, Supports Coordinators and Providers Perform Quality Management



Source: QA&I FY2018-2019